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Hispanic Caregivers' Experience of Pediatric Type 1 Diabetes: A Qualitative Study

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Abstract

Background: It is widely recognized that Type 1 Diabetes (T1D) outcomes are worse among Hispanic children; however, little is published about the perspectives of these patients and their caregivers.

Objective: Our intent was to characterize the lived experience of Hispanic caregivers of children with T1D, focusing on the role of language and culture and their perspectives on current medical care and alternative care models.

Subjects: We studied Hispanic caregivers of patients (age 2–17 years) with T1D of greater than 6 months' duration.

Methods: We completed semi-structured interviews and focus-groups of a purposive sample of 20 members of our population of interest. We developed a codebook and completed multidisciplinary consensus coding, then conducted iterative thematic analysis using qualitative software and discussion to generate themes.

Results: We gathered data from 20 Hispanic caregivers of T1D patients (11.37 ± 3.00 years old, 4.80 ± 2.84 years since diagnosis). 85% of caregivers were female, 80% preferred Spanish and 15% were college-educated. Our analysis yielded 4 themes across the participants: (1) Culturally-based nutrition challenges, (2) Social isolation and lack of support for T1D care, (3) Hesitancy to fully embrace diabetes technology, and (4) Differential views of care experience and providers.

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Overarching all of these themes was support for Hispanic group-based models of care tailored to address these concerns.

Conclusions: The unique concerns among Hispanic caregivers of children with T1D suggest the importance of culturally tailored interventions to improve care. With successful implementation, such interventions could diminish widening disparities in healthcare outcomes.

Keywords

Diabetes Mellitus, Type 1; Hispanics; Family Caregivers; Qualitative Research; Health Care Delivery

Introduction:

Disparities in healthcare and health outcomes in the United States (U.S.) on the basis of race, ethnicity, socioeconomic status, and language are well documented among children.¹ Researchers continue to examine the complex interplay of social factors in determining access, quality, and experiences of medical care among minority populations in the U.S. across the age range and spectrum of disease.^{2,3}

Childhood chronic disease brings about unique challenges and stressors on patients and families. Type 1 Diabetes (T1D) is among the most common childhood chronic diseases; successful management requires understanding of its treatment and constant vigilance by caregivers. Technological advances, including insulin pumps and continuous glucose monitors (CGM), have potential to improve outcomes, but diabetes technology uptake has been limited among minority patients.⁴⁻⁹ Data indicate that racial/ethnic and socioeconomic factors have a significant effect both on treatment modalities including use of technology and on outcomes including glycemic control as measured by hemoglobin A1c (HbA1c) and hospital admissions for complications like diabetic ketoacidosis (DKA).^{3,10-14}

Given the growth in the Hispanic community and the increase in prevalence and incidence in T1D among Hispanic youth, it is essential to understand these disparities.^{4,15-17} While the literature has grown regarding the unique experience of healthcare among the Hispanic population, qualitative studies in Hispanic youth with T1D are limited.^{4,15} Existing literature points to the unique features of Hispanic caregiver stress in pediatric chronic diseases such as asthma and cancer including struggles to incorporate traditional beliefs, access culturally appropriate education, and involve the extended family in the care support structure.^{18,19} However, there is limited literature focused on the Hispanic experience of caring for children with T1D specifically.²⁰⁻²⁴

In order to develop interventions and improve care among Hispanic patients with T1D, we must first understand their experience of care and the barriers to optimizing diabetes management.^{25,26} While there are multiple explanations posited for disparities including acculturation status, language and socioeconomic factors, and implicit biases^{27,28}, there have been limited descriptions of what parents and guardians feel would help and few interventions designed to narrow these gaps in care and outcomes.^{29,30} Some interventions have shown promise in other Hispanic chronic disease populations such as group-based care

delivery¹⁸; however, the majority of existing intervention literature in diabetes focuses on non-minority populations with T1D, or on adult Hispanic patients with Type 2 Diabetes (T2D).^{31,32}

Qualitative research offers a unique opportunity to capture perceptions, beliefs, and expectations of the target population.^{33,34} Furthermore, qualitative research is an important tool in developing interventions to optimize health outcomes and reduce disparities. Research in pediatrics requires engaging both patients and their caregivers, as effective management of disease across the age spectrum requires adult support. The objective of this study was to analyze the experiences of care as voiced by Hispanic caregivers of children with T1D.

Methods:

Study Design:

We conducted 1:1 semi-structured interviews and focus groups of 20 Hispanic caregivers of children with T1D in order to generate improved understanding of their experiences of diabetes care. The Institutional Review Board of Boston Children's Hospital approved this study.

Sample:

We utilized purposive sampling to recruit a sample of 20 Hispanic caregivers of children (ages 2–17 years) with T1D of greater than six months duration.³³ Twenty caregivers was our targeted sample size given commonly accepted qualitative research metrics for semi-structured interviews. Furthermore thematic saturation was clearly achieved before the conclusion of the coding process.³⁵

The research team contacted caregivers of approximately 100 unique patients; eligible caregivers included biological parents or other adults providing the majority of the diabetes care who self-identified as Hispanic and were able to speak/read English or Spanish. Caregivers of patients who had not had a diabetes clinic visit in the past year were not eligible for the study. Inclusion criteria were purposefully broad to capture a wide variety of experiences. Recruitment was conducted in person at clinic visits as well as by phone utilizing trained study personnel and interpreters as required. All caregivers signed informed consent forms and received \$25–50 compensation. Compensation was increased in the second stage of recruitment to enhance participation.

The families studied were cared for at a diabetes program in a large tertiary pediatric hospital in Boston, MA. This clinic serves a relatively small Hispanic population, with less than 10% of patients self-identifying as Hispanic. While interpreter services are readily available, there is limited access to Spanish-speaking providers. All T1D patients are assigned a pediatric endocrinologist, diabetes nurse educator, nutritionist, and social worker with whom they have the opportunity to meet with regularly.

Interview Guide and Procedures:

Based on an extensive review of the literature, multidisciplinary collaboration, and discussion with members of the Hispanic community, our research team developed a discussion guide. In this phenomenological approach to understand lived experience, interviews covered topics including experience of T1D, perceptions of care delivery including technology use and nutrition experiences, and novel care delivery methods including group-based care (see Table 1 for overview and Appendix 1 for guide).

Five trained interviewers conducted four focus groups and 12 semi-structured interviews from 2019 to 2020. Only one interviewer (EST) was a fellow in training in the diabetes clinic; however, she was not directly involved in the care of the families interviewed. Participants were assigned to groups or interviews based on availability. Conversations took place in person, on the phone, or via video conference depending upon participant availability and timing of interviews. Thirteen sessions were conducted in Spanish. Interviews were audio-recorded, transcribed, and translated into English for subsequent coding and analysis.

Data Analysis:

We conducted a thematic (framework) qualitative analysis. Qualitative research commonly uses thematic analysis as a means to allow investigators to compile data from a variety of participants and use the information to form broad conclusions about a subject area.^{35–38} The code set for thematic analysis was based upon a literature review; study authors expanded the initial code set throughout the analysis as necessary.

Each of the four female members of the multidisciplinary coding team (native Hispanic and Spanish-speaking social worker and pediatrics resident, research assistant, and Spanish-speaking pediatric endocrinologist) individually read and coded each of the transcripts in English. Through iterative team debriefings, the group triangulated the data and generated consensus coding of each transcript with saturation of thematic content. The team utilized NVivo 12 software (QSR International Pty Ltd, Victoria, Australia) for the next steps of thematic grouping and analysis.

In conjunction with a senior pediatric endocrinologist and qualitative researcher, the coding team met multiple times to condense codes into smaller groups in a second level coding analysis and ultimately identified final, key themes that best described and compiled the body of data. The study team kept an audit trail of the transcript review process that led to the final themes.

Results:

Participant Characteristics:

We studied 20 Hispanic caregivers of 19 patients (11.37 ± 3.00 years old, 4.80 ± 2.84 years since diagnosis). Of the 20 caregivers interviewed, 85% were female, 80% preferred Spanish and 15% were college-educated (see Table 2 and Table 3). Interviews were an average of 29 minutes; focus groups lasted an average of 53 minutes.

Thematic Analysis:

Our iterative thematic analysis process yielded four key themes consistent across the focus groups and interviews: (1) *Culturally-based nutrition challenges*, (2) *Social isolation and lack of support for T1D care*, (3) *Hesitancy to fully embrace diabetes technology*, and (4) *Deferential views of care experience and providers*. Overarching all of these themes was enthusiasm about Hispanic group-based models of care tailored to address these concerns.

Theme #1: Culturally-based nutrition challenges—When asked directly, participants did not identify any explicit role of their culture or of “being Hispanic” in the care of their child. However, interviewees referenced family beliefs, holidays, and nutrition as sources of Hispanic identity that interfaced with their diabetes care.

In particular, families discussed the challenges of acculturation and the changes that integration into American society introduced to their dietary habits.

I think for the most part... it all comes down to the eating, the things we eat within our culture.

(P1: Father, 7-year-old M)

It's not like other families and their food regimens...in my Latin family, you eat when you want.

(P7: Mother, 10-year-old F)

We have a different kind of diet; grains always have a lot of carbohydrates....so it is very difficult in that regard...

(P5: Mother, 11-year-old F)

Others expressed a desire to continue to eat foods from their native cultures but found it difficult in their American lives due to lack of resources or access to particular foods. Participants described the challenges of adapting their dietary patterns and lifestyle choices to a new diagnosis in their non-native country.

Over there, we cook the corn...I think it would be maybe a bit easier where I come from, but well, we are here, so we have to learn how it's done here.

(P2: Mother, 10-year-old F)

What happens is that we have to educate ourselves all the time because the food of the United States is very different from ours... it is part of our culture and changing it is very difficult.

(P7: Mother, 10-year-old F)

Yes, in my culture we eat a lot of vegetables...and they grew up eating like that. But then when he got here his mind changed, because they are asking for pizza, chicken, sandwich, things like that.

(P6: Mother, 13-year-old M)

Although most families recalled meeting with a member of the nutrition team at least once and generally said it was “good,” they remained uncertain how to manage their child's

food intake and ensure appropriate insulin dosing for traditional foods and expressed some unwillingness to change their diets entirely.

The nutritionist does her part giving us type of diet, adding carbohydrates, subtracting carbohydrates; but when we get home is a different story...Measuring carbohydrates is complicated.

(P10: Father, 13-year-old F)

And it's very difficult to talk to the doctors. They think, "Oh, but make some vegetables and a smaller portion and that's it," but it's not. It's very difficult with the nutrition, it's very difficult to explain to the American doctors that in our culture we eat like this and the family is not going to change what they do every day for another person.

(P7: Mother, 10-year-old F)

Theme #2: Social isolation and lack of support for T1D care—Participants widely reported a general lack of support from their partners/spouses and other relatives. Many participants had little extended family living in the U.S. There was a reported lack of diabetes education and management skills on the part of anyone other than the primary caregiver.

Yeah, I'm the one. And I'm always doing the checking and doing the calculations [while he is with my Mom]. His dad [helps]. But it's mostly me.

(P11: Mother, 13-year-old M)

I have not left him with anyone, other than the nurse or his father, since he was diagnosed with diabetes because no one knows how to calculate his carbohydrates...his sugar, the target during the day or night...

(P17: Mother, 12-year-old M)

Multiple participants reported that they were the sole caregiver for their child's diabetes and described the difficulties associated with feeling solely responsible for their child's care.

... sometimes I feel like I'm—I'm not alone because I know that God is helping me, but I am afraid to think that I might end up in a hospital or something and who is going to do my job?... there's nobody [else to help]. It's just me.

(P3: Mother, 11-year-old F)

I alone have had to face all that. Sometimes I don't sleep, when his glucose is very high...I set the alarm in case I fall asleep... I test him again because sometimes he becomes immune to insulin. I give him plenty of water and at midnight I get up and take the test again....

(P4: Mother, 11-year-old F)

I don't have anyone; I'm the only one who knows about his diabetes...

(P8: Mother, 5-year-old M)

Additionally, multiple participants expressed that a cultural lack of acceptance of the seriousness and permanency of T1D was a challenge for them to navigate. These participants endorsed that relatives did not accept their child's diagnosis despite repeated education attempts and were often dismissive of the management plan, rejecting the use of insulin in favor of folk remedies and proving unwilling to modify dietary practices.

For me [the hardest thing] has been making my family understand her diagnosis since there is no one who has type 1 in both families...Also culturally it is very difficult...there are relatives who tell me, "She is going to heal, it's going to heal" ...and they say "She's going to get better, give her this soup. Why can't you give her food? We are all eating."

(P7: Mother, 10-year-old F)

I thought it was going to be a passing thing, that it was going to go away.

(P18: Mother, 16-year-old M)

[My sister] tells me, "Why are you giving him insulin every time he eats? That's not right, it damages his organs." It drives me crazy...I even sent her something from Google... so she could see that he doesn't produce insulin and that's why we have to give it to him. But my sister is very stubborn she says, "Give him warm water with lemon."

(P8: Mother, 5-year-old M)

Parents and caregivers reported that their children with T1D experienced social isolation and challenges due to perceptions of others, and also highlighted a lack of peers with T1D.

She sometimes says like "Oh why do I have this?" or "Why am I the only one?"

(P13: Mother, 7-year-old F)

Theme #3: Hesitancy to fully embrace diabetes technology—Interviewees described their experiences with and opinions regarding insulin pumps and CGM. In these discussions, many Hispanic parents endorsed a positive perception of diabetes technology as a tool that streamlines care. However, others expressed concern regarding the physical burden of wearable technology, and many shared that their children refused to utilize these technologies out of embarrassment.

Many parents expressed distress surrounding insulin injections and were grateful that their use of CGM and insulin pumps reduced finger pricks and injections.

I don't feel so bad anymore because my daughter doesn't have to draw blood all the time.

(P7: Mother, 10-year-old F)

[The pump is] more comfortable for her too because there isn't so much injecting.

(P15: Mother, 12-year-old F)

Parents also shared that the use of technology has made them feel more at ease and reduced worries and anxieties surrounding their children's diabetes.

During the night [the CGM] is very successful... I do not know if it is because we are Hispanic or how we were raised, but we are extremely vigilant ... if we have to spend the night watching them, we do.

(P4: Mother, 11-year-old F)

...the sensor is wonderful, with the sensor if it is very low or high there is an alarm.

(P10: Father, 13-year-old F)

Additionally, parents shared that they and their children have appreciated how the technologies streamline their day-to-day care give their children more independence.

...the other [pump] is totally free of cables and we like it very much [because we can] do all kinds of activities...

(P4: Mother, 11-year-old F)

If she's with her friends...she has a phone, so she knows. If she is not with me, I know if she low or what is happening.

(P7: Mother, 10-year-old F)

However, a number of Hispanic parents endorsed that their children were embarrassed by wearing diabetes technology and did not want to be burdened by having to carry it around.

It was at school when she fell into depression, she was using the pump, the sensor and she did sports so it became difficult. There was a lot of bullying and it affected her.

(P10: Father, 13-year-old F)

He says that he doesn't want everyone to see [a pump]; he doesn't want to carry that around.

(P11: Mother, 13-year-old M)

Every time she puts in on, she tells me it itches, she cannot stand it, so we don't use it...she also feels embarrassed when she has the CGM in her body.

(P12: Father, 10-year-old F)

Further, a few parents were concerned that wearable technology would be a physical hindrance to their children's ability to play without restraint.

... he likes to be a kid, wrestle and play around. We knew after explaining it to him that probably that wouldn't be the best right now...

(P14: Father, 7-year-old M)

Lastly, some caregivers had the understanding that their child needed to achieve better glucose control before they would be eligible to use an insulin pump, and that their providers would let them know when they were "ready."

I think the pump is used when the sugar levels are under control, but his are very imbalanced.

(P1: Mother, 10-year-old M)

... she said my daughter is not ready yet...we are waiting for the doctor to let us know once my daughter is ready.”

(P12: Father, 10-year-old F)

Theme #4: Deferential views of care experience and providers—Interviewers spent time creating an open space to encourage participants to speak freely, including any constructive suggestions for improving care. However, rather than offering critiques, participants were universally positive about the care, showing and expressing respect for the providers and not citing language or interpreters as detracting from the care.

Excellent. I love it. Yes. They are very good doctors, good nurses, everyone...I have no complaints...

(P1: Mother, 10-year-old M)

I think they've done a phenomenal job in terms of communicating, helping out...

(P14: Father, 7-year-old M)

Participants also expressed a sense of connection with their child's provider with minimal difficulties in communication and described a beneficial relationship.

[The doctor and nurse have] both been phenomenal...extremely helpful, answering questions...I really have no complaints if anything praise.

(P4: Mother, 11-year-old F)

When I call for any reason, I get a call back...I've never had a hard time [communicating over the phone]. In fact, sometimes the person who answers speaks slowly and tries to understand me if they can't get an interpreter.

(P15: Mother, 12-year-old F)

A few participants expressed a hesitancy to ask for help and utilize on-call services but were quick to note that they believe that hesitancy is inherent to them, rather than a flaw in the system or providers.

But sometimes we underestimate ourselves so much that we put a barrier. “Oh, I dare not call because they may not understand me.” You limit yourself because you don't have all the information...but I don't think there is much of a barrier because always we find a way to communicate.

(P4: Mother, 11-year-old F)

I feel like they are always available [and] I should probably utilize them more than I do.

(P13: Mother, 7-year-old F)

When asked specifically about elements of the clinic or the care they have received that they would change, participants cite only generic complaints like wait time or scheduling availability.

What will I change? This has been a blessing from heaven...

(P6: Mother, 13-year-old M)

... sometimes I have to wait, but it's normal. If I complained about the wait would be like ... I don't know.

(P15: Mother, 12-year-old F)

To have a clinic closer to home. It is the only thing I would say...

(P1: Mother, 10-year-old M)

In addition to these specific themes, when asked specifically about novel care methods including group-based medical care, participants expressed widespread support for shared medical appointments, classes about diabetes related nutrition and technology, and support groups tailored to Hispanic families.

Sometimes we learn more in a group setting—hearing other people's opinions.

(P1: Mother, 10-year-old M)

Like maybe they have a good system...even to the extent that maybe one of the parents has a child probably who's had the pump ever since a very young age and that could help reiterate and reinforce to show him ...Positive reinforcement that we could feed off each other.

(P14: Father, 7-year-old M)

...I have a way of treating, I have an idea, I have a knowledge, but maybe there are other people who have more knowledge. I can help someone else and that person can help me.

(P19: Mother, 13-year-old F)

They additionally noted the degree of emotional support that could be derived in a group setting for both themselves and their children.

And sometimes they do not feel understood, and they believe that they are the only ones, that the world is going to end because they are the only ones on earth with that condition, but there are many others...we learn a lot by talking with other people and give ideas.

(P4: Mother, 11-year-old F)

It would be as if one of my dreams come true, for my son to see that he is not alone...let him see other children...so that he sees that it is not only him, that there are more people with that condition.

(P20: Mother, 16-year-old M)

Discussion:

This qualitative study elucidated the experiences of Hispanic caregivers of children and adolescents with T1D receiving care at a large U.S. pediatric diabetes center. While many of the challenges expressed by caregivers are universal, this analysis highlights previously identified challenges in multiple domains that crossed the wide range of developmental

stages represented in our sample of Hispanic caregivers— including nutrition, isolation, and diabetes technology – which may provide guidance for developing culturally tailored interventions to improve care delivery and outcomes for this population.

Hispanic caregivers expressed a variety of concerns surrounding nutrition, particularly around the types of food they prepare as well as their cultural eating patterns. While many had made progress in their understanding of how to adapt to the nutrition demands of T1D, they acknowledged that this remained a major stressor and that the guidance that they received from nutritional education was of limited utility.

The challenges of applying Western-based nutritional advice has been identified in other qualitative research in the field.³⁹ Although Hispanic youth with diabetes are more likely to have T1D than T2D, the majority of published research in the field addresses nutrition and lifestyle interventions via “community-based” and “culturally grounded” weight loss programs with group-based nutrition and health classes serving families of obese Hispanic adolescents to prevent T2D.^{17,40–43}

The experiences expressed by participants in our study suggest that Hispanic families of children with T1D would benefit from tailored, culturally-relevant nutrition education. Such options may be available at programs with larger Hispanic communities, but further studies are needed to provide curricular roadmaps. Smaller programs may benefit from virtual versions of similar programming customized for their program’s specific ethnic make-up.

A second major theme common across the majority of participants was a sense of social isolation among caregivers who reported that other family or community members provided them with limited support as cultural perceptions of illness impacted understanding of the importance of adherence to the patient’s treatment. Additionally, parents expressed a lack of proper education and confidence surrounding diabetes management skills of other relatives.

A study of low-income families of patients with T1D found higher levels of parental concern regarding their child’s diabetes. There were significant differences between caregivers on the basis of ethnicity with Hispanic families tending to report “recognizing the importance of family” as a factor that affected their care experience.²³ Qualitative research conducted among Hispanic patients with T2D has echoed these sentiments, with participants reporting isolation due to family and friends’ limited understanding of the disease. The role of the social support system was identified in previous research as being important in a patient’s ability to successfully manage their diabetes, further highlighting these challenges.^{20, 39} In addition to mental health support services for primary caregivers, increased culturally tailored education for non-primary caregivers about diabetes management and pathophysiology may help to improve understanding of the significance and importance of proper adherence to treatment and thereby decrease the burden on primary caregivers.

A third key theme generated from the experiences of our study participants addressed concerns about diabetes technology. Many parents described their children as being fearful of any physical evidence of diabetes on the body; participants also expressed a perception that they were not ready for technology.

Our findings evoke the question of whether Hispanic youth with T1D experience these worries in a unique manner. In a recent study of the views of Hispanic adolescents with T1D, participants similarly expressed that one of the main challenges of having T1D was “feeling different or alone” and described a fear that their peers would see them as different because of their diabetes.²¹ A study of diabetes technology use by diverse families of low SES found that only 2 out of 7 Hispanic, compared to 7 out of 7 non-Hispanic white families, chose to utilize insulin pumps when offered. The Hispanic families cited a concern that pumps would have a negative impact on body image and cause discomfort with sports.²³

Several prior studies have demonstrated disparities in the use of diabetes technology, correlating pump and CGM use with demographic factors including race/ethnicity, income, insurance status, language, and parent education.^{5,6,9,10,44–47} There is evidence from the literature that provider bias may also affect the decision to start pump therapy and that perceptions of patients may impact intensity of diabetes regimen.^{9,48} Even among Hispanic children that receive pump therapy, diabetes control is more likely to be sub-optimal than it is among their non-Hispanic white counterparts.⁴⁹

Future work should explore the differences in attitudes toward technology among Hispanic patients of different developmental stages, cultural backgrounds, immigration status, and other socioeconomic factors. Additionally, researchers should investigate the experience and perspective of clinicians to understand choices about when and how to offer diabetes technology to Hispanic families. Research should address how training materials and strategies can be redesigned to accommodate these factors and enable introduction of diabetes technology to Hispanic families while also further examining the underpinnings of and potential solutions to body image and physical comfort concerns.

Despite reported barriers in domains of nutrition, social support, and technology, our fourth theme reflected deference, respect and gratitude for health care received. It is important to note that interviews were completed by members of the study team who were affiliated with the diabetes program and participants received compensation for their participation. However, in the literature, the tendency not to criticize health care is especially pronounced in families with more recent immigration status.⁵⁰ In pediatrics, parents are seen as valuable stakeholders in care of their children, and their feedback is crucial to improve clinical practice and provide optimal care. Our findings suggest that Hispanic caregivers may not feel empowered to provide criticism of the care they have received, and further investigations are required to characterize this finding and identify strategies that enable all caregivers to share constructive feedback with providers.

In terms of published interventions, limited studies suggest that community-based and cultural and language-inclusive supports for Hispanic families caring for children with diabetes can improve care experience and outcomes. The notion of “cultural competence” is well-described in the literature and emphasizes the need to value culture and adapt services according to specific needs.^{51,52} However, the literature in this field is limited by small sample sizes and minimal diversity of intervention types, with most intervention based studies described in adult and T2D Hispanic populations.^{29,31,32,53,54} Small studies have investigated the value of a Spanish-language based pediatric T1D clinic and have found that

eliminating the language barrier increased the percentage of Spanish-speaking patients who achieved target HbA1c levels.²⁹

In addition to addressing existing challenges, our study sought to understand the openness of Hispanic families to alternative care models. When the idea was suggested, participants expressed particular interest in group-based care. The need for social support is not unique to Hispanic families; however, the literature suggests that this tendency towards group-based and culturally congruent support systems is consistent among Hispanic families.^{23,30} There are limited trials of group-based interventions and most take place in adult populations with T2D and/or do not address application to Hispanic cultures.^{55–58} One recent study found that shared medical appointments for Hispanic patients were effective in decreasing HbA1c among the child participants and increasing diabetes technology use in both children and adolescents, with further benefits in relationship-building between parents and caregivers who shared cultural and language backgrounds.⁵⁹

Our study has several unique strengths. There is a lack of literature surrounding the lived experience of Hispanic caregivers of children with T1D. Our study closely examines the challenges and concerns among this vulnerable population and contributes novel perspectives. Additionally, the utilization of both semi-structured interviews and focus group methodology enabled the generation of rich qualitative data, which was further enhanced by our diverse multidisciplinary research team that completed interviews in the participants' preferred language; the majority of interviews completed in Spanish were conducted by a native speaker with extensive professional experience in social work and personal cultural experience.

Limitations of our study include its small sample size and recruitment challenges. While we did achieve thematic saturation among our group of participants and incorporated the opinions of caregivers with a wide variety of experiences, we are not able to characterize the ways in which participants differed from non-participants. Recruitment challenges are not unique to our cohort; recruitment and inclusion of minority populations in research is a systemic concern. Additionally, our study was performed at a single center with a small Hispanic population and therefore may not adequately express the opinions and concerns of this demographic more broadly. We also have limited data on the participants (i.e. country of origin and socioeconomic status); more complete data would enable better contextualization of the study. Future research should expand beyond our center to a more nationally representative cohort and could additionally explore the experiences of patients and providers, as they may be distinct from that of the caregivers.

The voices of Hispanic caregivers conveyed through this study provide a window into understanding how we can improve care in the pediatric setting via the delivery of innovative culturally competent curricula surrounding nutrition and technology, while also incorporating novel care delivery methods such as shared medical appointments and group-based classes, in order to better reach our Hispanic patients and their families and ultimately lessen disparities in T1D care and outcome measures.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations:

CGM	Continuous glucose monitor
DKA	Diabetic ketoacidosis
HbA1c	Hemoglobin A1C
T1D	Type 1 diabetes
T2D	Type 2 diabetes
U.S.	United States

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Table 1:

Qualitative Interview/Focus Group Topic Guide

Topic Area	Talking Points
Experience of Type 1 Diabetes	<ul style="list-style-type: none">• Challenges of T1D care• Role of family in T1D care• Role of community in T1D care• Role of ethnicity/language/culture in T1D care
Perceptions of Care Delivery	<ul style="list-style-type: none">• Care providers• Insulin regimen• Technology use• Insurance issues• Language issues
Novel Care Delivery Models	<ul style="list-style-type: none">• Caregiver recommended changes• Tele-health• Facebook groups• Group visits

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Table 2:

Qualitative Interview/Focus Group Participant Demographics (n=20)

Demographic Categories	Frequency	Percentage
Gender		
Male	3	15%
Female	17	85%
Age (Years)		
25–34	2	10%
35–44	14	70%
45–55	2	10%
56–65	1	5%
Ethnicity *		
Puerto Rican	3	15%
Other Hispanic, Latino, or Spanish Origin **	17	85%
Education Level *		
Grade School	4	20%
High School	5	25%
Some College	4	20%
2-year College Degree	2	10%
4-year College Degree	3	15%
Some Graduate or Professional School	1	5%
Race		
White	8	40%
American Indian or Alaska Native	1	5%
Other ***	11	55%
Language Preferred for Healthcare Conversations		
Spanish	16	80%
English	4	20%
Participation Type		
Focus Group	8	40%
Interview	12	60%
Participation Language		
English	3	15%
Spanish	17	85%

* One participant declined to answer this question

** Specified options included: Mexican/Mexican American/Chicano; Puerto Rican; Cuban; Another Hispanic/Latino/Spanish origin

*** Specified options included: White; Black/African American; Asian; Native Hawaiian or other Pacific Islander; American Indian or Alaska Native; Other

Table 3:

Patient Demographics (n=19)*

Demographic Categories	Frequency	Percentage
Gender		
Male	8	42%
Female	11	58%
Age (Years)		
5.0–9.0	3	16%
9.1–12.0	8	42%
12.1	8	42%
Duration of Diabetes (Years)		
<3.0	6	31.6%
3.1–6.0	7	36.8%
6.1	6	31.6%
Most Recent HbA1c**		
7.5	3	15.8%
7.6–9.0	9	47.4%
9.1–10	4	21.1%
10.1	3	15.8%
Continuous Glucose Monitor Use***		
Yes	9	47%
No	10	53%
Insulin Pump Use***		
Yes	5	26%
No	14	74%

* Note: Two of the study participants were caregivers of the same child with diabetes.

** According to pre-existing EMR data, not collected by study authors. Value chosen based on chart data closest to interview date.

*** Assessed via EMR data at time of HbA1c measurement.